

# UMDNJ-Robert Wood Johnson Medical School

## Kernicterus Research and Prevention Center



There has been recent concern in the United States over increased reports of kernicterus. Kernicterus is a preventable disability that results from brain damage caused by severe levels of jaundice. Symptoms of kernicterus include athetoid cerebral palsy, sensorineural hearing loss, gaze paresis, dental dysplasia, and mental retardation. For more information visit:

[www.cdc.gov/ncbddd/dd/kernicterus.htm](http://www.cdc.gov/ncbddd/dd/kernicterus.htm)

Kernicterus is easily prevented. Jaundice can be reduced to safe levels with appropriate treatment such as phototherapy or an exchange transfusion.

One objective of Healthy People 2010 is to reduce or eliminate preventable neurodevelopmental disability in infancy. The Centers for Disease Control and Prevention (CDC) is funding the development of kernicterus research and prevention programs. Two centers have been funded; one is in New Jersey and the other is in Pennsylvania.

The UMDNJ-Robert Wood Johnson Medical School Kernicterus Research and Prevention Center, New Brunswick, New Jersey will conduct the following projects:

### Monitoring Activities

The incidence of kernicterus and severe hyperbilirubinemia in neonates in the United States is not known because, to date, these conditions have not been routinely followed in this population.

The New Jersey center, along with the New Jersey Department of Health and Senior Services, will develop and implement a monitoring system to track and analyze new cases of kernicterus and severe hyperbilirubinemia, defined as total bilirubin level during the neonatal period of  $\geq 20$  mg/dl. The area to be served by this program includes the entire state of New Jersey.

Preliminary research on infants born from 1992 through 2001 revealed 82 kernicterus cases, with 7.5 cases for each 100,000 live births. There was significant variation in rates by race and ethnicity. The lowest rate was among Hispanics and the highest among Asians.

### Epidemiologic Study

The main goal of this project is to track cases of severe hyperbilirubinemia and kernicterus in order to identify risk factors and ways to prevent these conditions.

The New Jersey center will study the epidemiology of kernicterus morbidity and mortality by using available national and regional databases. All infants with kernicterus in New Jersey from 1992 through 2004 will be looked at using maternal, neonatal, and infant medical records, as well as a survey of parents. The same methods will also be applied to study new cases of severe hyperbilirubinemia.

### Special Projects

Kernicterus is a major public health concern because it causes permanent brain damage and impairs a child's quality of life. The New Jersey kernicterus research and prevention center will establish kernicterus education programs for medical students, fellows, primary care physicians, and parents. In addition, a support program for families of children who have kernicterus will be organized.

### Sharing Information

The New Jersey center plans to train nurses, physicians, educators, and other health care providers to enhance the awareness of risk factors for neonatal hyperbilirubinemia. Information will be shared through mailings to parents, support groups, and the media; scientific publications and presentations at professional conferences will also be provided.

### For further information, please contact:

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